Lyme Disease Advisory Committee
Minutes of the November 28, 2001 Meeting
Department of Health Services, Sacramento

The fifth meeting of the Lyme Disease Advisory Committee (LDAC) was held on November 28, 2001, in Sacramento, California.

Committee members
Jean Hubbard, Lyme Disease Resource Center
Vicki Kramer, Ph.D., California Department of Health Services
Robert Lane, Ph.D., University of California, Berkeley
Lee Lull, Lyme Disease Support Network
Susie Merrill, Lyme Disease Support Network
Christian Parlier, Lyme Disease Support Network
Raphael Stricker, M.D., California Medical Association

Committee member absent
Scott Morrow, M.D., California Conference of Local Health Officers

Other attendees
Anne Kjemtrup, D.V.M., Ph.D., California Department of Health Services
Peter Mackler, California Department of Health Services
Approximately 35 people representing the interested public and public agencies

I. Opening comments

Dr. Lane, Chair, called the meeting to order at 10:00 am. He introduced members of the committee and said that Dr. Morrow was unable to attend due to illness. He reviewed the committee's mission to educate California's medical community and its citizens about Lyme disease (LD), its hazards and prevention, noting that it was among the committee's specific aims to work together to improve things that aren't going well now, including those related to treatment of the disease. He invited guests to share their concerns during the public comment period scheduled for the end of the meeting and also to speak individually with committee members during breaks. He added that he would remain for extended discussions afterward.

II. Review of minutes of 8/07/01 meeting

Dr. Kjemtrup reported that the minutes of the August 7, 2001 meeting had been approved via email and voice mail. Dr. Kramer clarified that all members had responded at some point. The minutes were unanimously approved as written.

III. Discussion of procedural motions

Mr. Parlier had emailed the committee a procedural motion reading, “Whenever mass mailings of educational materials occur, please include members of the LDAC at the same time.” As discussion began, Mr. Parlier amended his motion to add that “educational materials be approved by the committee before being mailed.” He observed that this should be standard procedure. Ms. Hubbard suggested the language be extended to include all DHS educational materials regarding tick-borne diseases. Dr. Lane agreed, noting that such approval of educational materials is part of the committee’s function and needs to occur before their distribution. Dr. Kramer questioned whether the intent was also to require re-approval prior to re-distribution; Dr. Lane clarified that it would not, only initially.

Mr. Parlier said that because of problems with emails, his motion still included that all draft and final versions should be made available to committee members in hard copy as well as via email. Ms. Hubbard seconded the combined motion. Dr. Lane asked whether members agreed with the general principles – that “the committee will approve all educational materials about tick-borne diseases prior to their distribution, and then, to protect against problems with emails, each member will receive hard copies.” The committee unanimously approved these procedural principles.

Later, during discussion of educational materials that had been distributed without review or approval by the committee (see discussion of LD Epidemiology Update article below), Dr. Kramer asked that the motion be reworded. She said that although she appreciated the input, advice and comments given by all members and agreed that in the future DHS would not send out new material without members knowing about it, having an opportunity to read it and give their advice, she was concerned that obtaining full approval would delay DHS’ educational work. Ms. Hubbard thought accuracy was even more important than speed. Mr. Parlier said he didn’t want to mitigate the term “advisory.” He thought the spirit of the bill and its language lend greater weight to what the committee was comprised to do than had been occurring, adding that sometimes it feels “as if we’re just a thorn in the elephant’s foot.”

Dr. Kramer pointed out that it has often been impossible to obtain unanimous approval. She felt it wouldn’t be workable to obtain a vote every time DHS wants to provide educational materials. For example, she and Dr. Kjemtrup get input from different members wanting exactly different things in the brochure, and sometimes members fail to email their approval even of the minutes. Ms. Hubbard agreed that it cannot be done via email. She observed that obtaining input from individuals, especially via email, and just selecting out what you want from the pool of suggestions differs significantly from actually understanding advice developed through discussion among committee members during meetings. Given the complexity of the issues and data pertaining to tick-borne diseases, the serious

consequences of misleading people, and the diversity of the committee's expertise, she said, "We really need to get together and figure out what our advice should be by talking with each other." Dr. Lane concurred, noting that while Dr. Kramer was correct in saying the committee wouldn't reach unanimity on many of these topics, it was nonetheless important to subject all educational materials to the committee process. Ms. Hubbard added that to whatever extent possible, members would be working towards achieving the full committee's advice to DHS.

The motion was eventually amended to read, "Prior to their distribution, the committee will review, discuss and provide its advice to DHS regarding all tick-borne disease educational materials. The LDAC will be included in all mailings, both in hard copy and via email." It passed unanimously.

Ms. Lull suggested a second procedural clarification. She noted that the California Lyme community had hoped to have some input prior to each vote. Since that would be cumbersome, she suggested that motions not be considered permanent decisions until the committee had opportunity to hear any additional evidence or objections from the community. Dr. Kramer observed that motions can certainly be amended after votes are taken.

IV. Department of Health Services (DHS) Progress Report

Dr. Kjemtrup observed that this meeting marked the 1-year anniversary of LDAC, an appropriate time to review how DHS has responded to goals set by the committee in terms of educating the general public and the medical community.

Educating the General Public: In response to requests by LDAC, DHS has increased the frequency of press releases about Lyme disease (LD). There are now two per year. As requested at the August 7 meeting, the Fall press release about the adult tick season includes the color-coded tick map of California, depicting counties where *Ixodes pacificus* ticks have been found in light green and counties where ticks have tested positive for *B. burgdorferi* in dark green. She displayed the tick map that would accompany the Fall press release and would soon be added to the website as well. Its legend read, "Approximately 2% of adult *Ixodes pacificus* ticks are infected with *B. burgdorferi*; the infection rate may be lower or higher in some locales."

This legend occasioned considerable discussion about how tick infectivity rates should be described in various contexts. Ms. Lull thought it would be misleading to specify the 2% infection figure for adult ticks because people will remember it as representing the degree of risk. Ms Merrill agreed. She noted that although everyone agrees that the nymph is the most important stage of the vector, DHS continues to emphasize this infection rate for adult ticks. Because it's so low, doctors believe no one can get infected. Ms. Hubbard added that, since DHS then compares the 2% rate to adult tick infection rates in the Northeast where they tend to be twice those in nymphs, the percentage figure also falsely carries the

implication that risk is dramatically lower here than there. The more appropriate comparison of infection rates is between nymphs.

Dr. Lane agreed that mentioning only adult infection rates in any context would be misleading, although clearly adult ticks do infect Californians. In the Northeast, although infection rates in adult ticks average about 50%, they seldom infect people. Instead, even there most people are infected by nymphs, whose infection rates in the Northeast range between 10 and 30% and probably average around 15 to 25%, which is not a great deal higher than the rates in some California areas.

It was agreed to delete the current legend (see above) from the map, and several alternatives were discussed. Dr. Lane observed that one source of confusion in deciding on an adequate legend for the map was that, although all agreed it was important to emphasize information about nymphal tick infection rates, the tick map itself reflects data derived mainly from adult ticks. Dr. Kjemtrup added that the data on nymphal infection rates in California are currently too limited to generate a similar map for nymphal ticks. She noted that the Fall press release was intended to alert people to the increased seasonal activity of adult ticks and the Spring press release will emphasize nymphal activity. Dr. Kramer pointed out that since in a press release the map has space for only a brief legend , some of the other suggestions were more pertinent for the brochure or accompanying the map on the website. For the reader's convenience, a few of the suggestions are reported in the discussion on the DHS LD brochure below.

The committee agreed on several other points:

1) The number of counties should be specified in parentheses after each category on the map.
2) Informative, detailed discussions about rates of tick infectivity should accompany the map where space permits, e.g., on the website and in the brochure and other educational materials.
3) The nymphal tick infects the most people and, in California, unlike the northeastern United States (U.S.), nymphal tick populations tend to have a higher rate of infection than the adult tick populations (at least in those regions of the state where the nymphal tick population has been adequately studied).
4) While it is important to educate people about adult ticks and the adult tick season, it needs to be done without minimizing the overall risk of infection in California. It is therefore misleading to describe adult tick infection rates without also describing rates of infection in the more important vector, the nymph.
5) In the Fall press release, the legend for the tick map should state a) that infection rates for both nymphal and adult ticks have been well-studied in only one county, b) that the specific information now available can be found on DHS' website [give web address], and c) that the website is continually updated as new information becomes available. This point was in the form of a formal motion that passed unanimously.

Dr. Stricker observed that people like to see numbers. He wondered whether, on the website's tick map, they could just click on a county to get specific information. Dr. Kramer said she had spoken with the person working on the website about doing this, but was told it would be complicated to achieve this in a short time frame. The tick database will be organized by counties and in fact will give specific information about localities within the counties where ticks have been collected and tested. The plan is to get the database up quickly and develop refinements over time. Mr. Parlier wondered whether the database now includes Dr. Lane's data on nymphs. Dr. Kramer said they weren't included yet but would be soon -- the more complete the database, the better. Dr. Kjemtrup noted that in response to Ms. Lull's motion of August 7, letters were mailed to nine agencies that test ticks, urging them to forward their data to DHS for inclusion in the database. Ms. Hubbard and Ms. Merrill observed that the letter didn't ask the labs to alert the press when a tick tests positive, which had been that motion's original intent. Dr. Kramer said that specific request would need to be addressed to a different person within each agency and would be mailed soon.

Dr. Kjemtrup added that DHS has expanded its website to include a section specifically on Lyme disease. In addition to the tick database, it will include the minutes of the LDAC meetings, the tick map and the brochure, as well as some of the additional material DHS develops. It already includes the Epidemiology Update article, the vaccine recommendations, and some of the LDAC minutes. Additionally, as per another LDAC motion, DHS has mailed a letter to the U.S. Forest service encouraging them to post the tick warning signs and literature DHS provides them.

General DHS Activities: Dr. Kjemtrup reported that DHS biologist Renjie Hu had addressed 120 people attending the Mosquito and Vector Control District's (MVCD) continuing education workshop on the topic "Tick-borne Disease Surveillance, Concepts and Sampling Methods." DHS biologist Lucia Hui continued distributing the Department's monthly Vector-Borne Disease Bulletin to public health and MVCD agencies within California and nation-wide.

DHS' tick surveillance continued as well: DHS biologist Mark Novak looked for *Ixodes pacificus* adults in Alpine County in early November and was unable to find any. DHS biologist Marty Castro continued ongoing surveillance of *Ixodes pacificus* nymphs as part of a project with Dr. Lane in Hendy Woods State Park in Mendocino County and also worked with the Marin/Sonoma MVCD collecting ticks for an investigation following up a case of human granulocytic ehrlichiosis in a person in Marin County.

Educating the Medical Community: Dr. Kjemtrup reported that DHS' efforts to educate the medical community had already begun. Responding to one of LDAC's goal items, she had submitted an update on the epidemiology of LD in California to the California Medical Board's quarterly newsletter "Action Report," which reaches

50,000 physicians, and it was published in the most recent issue. It included the tick-infectivity map.

V. Proposed Physician Education Program

Dr. Kjemtrup had also drafted a proposal for a physician education program that would contain a component designed to assess the effectiveness of DHS' educational activities. She presented her proposal to the committee for review.

Problem statement and outline of proposal: Dr. Kjemtrup pointed out that it is apparent that LD is under-reported in California. Despite documented epidemiological elements favorable for the transmission of LD and an expanding population increasingly in contact with natural environments, the yearly number of reported cases has decreased from 347 in 1990 to less than 100 cases each year since 1995. A possible explanation for under-reporting of the disease may simply be because physicians in California are unaware of the occurrence of LD in this state. She noted factors that might be contributing to their lack of awareness: The focus of most epidemiologic studies on LD in the eastern United States may have left the impression that it's not a western problem, or perhaps physicians haven't been able to assess a patient's risk for acquiring LD because county incidence rates and tick infectivity data haven't reached them. DHS' educational activities could change that.

Because an education program aimed at all of California's 60,000 physicians would be costly; she proposed developing an intervention-type study to assess the impact on the medical community of DHS' educational activities. The study would target a representative sample of perhaps 2,500 California physicians and assess their current knowledge and attitudes about LD as well as some specific behaviors and skills. DHS would then provide half of the group with educational materials before reassessing the entire group one year later.

Goals and outcome objectives: The final, overall goal, she said, would be to observe a better understanding of LD risk in California from increased reporting. The primary outcome objective would be to show at least a two-fold increase in reported cases.

Physician Questionnaire: Dr. Kjemtrup asked the committee to help develop a Physician Questionnaire in the context of the intervention study. It could assess knowledge and attitude factors such as: Are they aware that LD exists in California? Are they confident in their ability to recognize LD in a patient? Are they aware of risk factors so they can educate patients most at risk? Are they aware of ways to avoid tick bites and infection? Can they communicate these effectively to their patients? Do they know that LD is reportable? It could also assess behavior and skill factors including: Have they ever diagnosed a patient with LD? Have they ever diagnosed other tick-borne diseases? Have they reported a case? If there are barriers to diagnosis and reporting, what are they?

She asked the committee also to consider good avenues for getting LD information to physicians, because “it’s one thing to provide information, another to get them to read it.” She suggested providing them with tick-ID cards, the brochure and a gallery of EM examples, as well as a regular tick-borne disease newsletter that might include updates on reported cases, specific disease updates and guest columnists discussing diagnostic and treatment quandaries associated with vector-borne diseases. Responses to the Questionnaire might suggest other ideas.

Discussion of LD Epidemiology Update article: Ms. Hubbard had concerns about the Epidemiology Update article. She found it strange, first, that everyone involved in the DHS approval process had thought it okay to publish a paper telling physicians that the infection rate for nymphs in Mendocino County was 41.3%. Ms. Merrill observed that this was in keeping with the goal of raising awareness and would get their attention. Ms. Hubbard agreed it would do that initially, but thought over time the exaggeration of risk could make it more difficult for them to take seriously the true data, which in Mendocino are bad enough. She thought it more worrisome, since the article begins and ends with paragraphs about the vaccine, that physicians might think such a dramatic figure justified recommending the vaccine to Mendocino residents and employers might even require it for their outdoor workers.

Dr. Kramer explained that the intent was to begin the article with an item that is new to Lyme disease or that physicians may have recently heard about to get their attention. Also, physicians need to know a vaccine is available, and she noted the article states, “DHS does not recommend the LD vaccine for routine use anywhere in California.” Ms. Hubbard pointed out that the word “routine” is in bold face, strongly implying exceptions. Because DHS already has so much information about it on their website, she thought the committee should discuss the vaccine soon. She noted that not only is there a class action suit against it because people say it has harmed them, but apparently it also interferes with serologic testing for infection, a significant problem because the vaccine is far from perfectly protective. Dr. Kramer reported that the vaccine guidelines on the website had been updated since the class action suit. Dr. Lane observed that DHS had to develop guidelines about the vaccine to be a responsible health department and that he didn’t think the intent of the article was to advocate its use.

Ms. Hubbard went on to say that what upset her most were the references. Those described as “discussing diagnosis and treatment” she thought unacceptable because they are, in her opinion, infamous worldwide as being an orchestrated attack against diagnosing LD sensitively and treating it adequately. She was dismayed that DHS has essentially told 50,000 California physicians – as well as the Medical Board, which makes decisions about both the Standards of Care and licensure of physicians -- that the Department agrees with this damaging point of view. She thought it likely Drs. Kramer and Kjemtrup didn’t appreciate the potential of these references and hoped they would discuss them with her. Dr. Kramer

agreed and added it would help with future articles if Ms. Hubbard would specify in writing the aspects of the Update article that troubled her. Dr. Lane observed that Ms. Hubbard's concerns underlined the importance of reviewing all educational materials prior to their distribution, including references. He suggested the whole committee discuss these references specifically, as such a discussion would be pertinent to future publications.

Ms. Hubbard asked also that the committee consider how to correct the effects of this publication. She thought it would require getting a revised version out to the same audiences as soon as possible, perhaps for the spring Action Report. She asked everyone to consider which articles to include in the reference list and also that they review the Update article itself with an eye to improving it. Dr. Lane suggested this be an agenda item. Mr. Parlier moved it be on the agenda for the next meeting and that, given its importance, the committee take as much time as needed. Dr. Lane thought that a reasonable plan. He added that failure to present both sides of a controversy, not just the side one happens to agree with, results in loss of credibility; similarly it is important to provide references expressing the differing points of view. Dr. Stricker agreed. He thought it less likely that the CMB Action Report would publish another article on LD in the near future than that they would publish a correction box containing a statement to the effect that there was a controversy concerning the references and providing additional ones. Dr. Kramer suggested VBDS contact the Action Report to request space in an upcoming issue and that other members consider which articles should be referenced. Ms. Hubbard said she would mail everyone, before the next meeting, copies of articles she would like members to consider.

Ms. Hubbard addressed Dr. Kramer regarding a discrepancy between what Dr. Kramer had told the committee and what actually transpired with regard to the publication of the paper on LD by Drs. Fritz and Vugia. According to Ms. Hubbard, Dr. Kramer had refused to allow the LDAC to review the paper prior to its publication, stating that it was not intended as educational material but rather as a paper written by two individuals, and that it would carry a disclaimer stating that it did not necessarily represent the views of the DHS. As published, Ms. Hubbard pointed out, it carries no disclaimer and appears to be speaking to California physicians in an educational manner. Dr. Kramer responded that she had denied LDAC's request for review of the article ("Clinical issues in Lyme borreliosis: A California perspective") because it is was written for publication in a professional, scientific, peer-reviewed journal and it is standard procedure not to release such an article until it has been reviewed and published. She added that there is no disclaimer because the document had been officially reviewed and approved by DHS management, and that she had not been aware that this decision had been made nor of this DHS policy at the time of the LDAC discussion about the paper in May (5/11/01). Ms. Hubbard voiced shock on Dr. Kramer's behalf that her department had placed her in this position.

VI. Announcement from the office of DHS Director Dr. Bonta

Dr. Lane introduced Mr. Peter Mackler from the office of DHS Director Dr Bonta. Mr. Mackler, on behalf of the Director, thanked everyone for participating. He commented that the committee was one of the most passionate of the 62-odd commissions and advisory boards in the State Department of Health. He thanked everyone for bringing their passion and compassion, as well as their experience and expertise, to the table. He pointed out the importance of reminding ourselves that our real enemy is LD, and that we all share the dream, the hope and job of eliminating it in California.

He announced that the Director had just this day signed a new appointment to the LDAC, Dr. James Miller, Professor Emeritus from UCLA. Dr. Miller has accepted the appointment and will be joining the committee for its next meeting. The announcement was greeted with enthusiasm.

V. Physician Education Program, continued

Dr. Lane asked Dr. Kjemtrup to continue with discussion about the Physician Education Program and the questionnaire. Dr. Kjemtrup reiterated that the purpose of the questionnaire is to assess the effectiveness of DHS' educational activities, a crucial step in obtaining additional funding if needed. She asked the committee to review suggested questions (which she would email) for evaluation in that context. To increase the response rate from physicians, she thought the questionnaire should be kept very simple and very short, not like a test, with questions that are to the point and that can be reassessed later. She and Dr. Kramer asked members to email comments and suggestions on the proposal and questionnaire to everyone for discussion so that revisions can be made prior to the next meeting.

Ms. Merrill commented that just mailing the questionnaire itself would raise awareness among physicians that DHS does believe there is LD in California. Ms. Lull wondered what response rate was expected. Dr. Kjemtrup thought 50% would be doing well; Dr. Stricker estimated about 20%. Drs. Lane and Stricker wondered which specialties should be represented in the sample of 2,500, and Dr. Kjemtrup said she'd like the committee's advice about that.

Ms. Lull again raised the idea of educating physicians by providing seminars utilizing the expertise of physicians like Dr. Stricker who see the whole gamut of presentations among many patients. She pointed out that this kind of active participation, where they can ask questions and have them answered, is how doctors really learn. The idea had been presented as a motion by Ms. Lull at the August meeting and tabled for further discussion when physician education was addressed. Dr. Lane recalled that many had agreed with the idea. He suggested developing such seminars, and also developing a video of the live seminars, should be added to the agenda, if possible for the next meeting.

VII. Discussion of DHS LD brochure

Because there was insufficient time at the meeting for a complete review of the most recent draft of the brochure, the committee considered various means for more fully incorporating members' suggestions and decided on Dr. Kramer's suggestion of working through the editing function of an emailed attachment, as is done with the minutes. Dr. Kjemtrup offered to incorporate suggestions from today's meeting, as well as earlier input, into a draft to serve as the baseline attachment for everyone to edit. Dr. Kramer hoped that members would spend no more than 3 to 4 weeks on this revision process, after which Dr. Kjemtrup would be able to return the revised draft to everyone 2 to 3 weeks before the next meeting. The draft could then be fine-tuned in discussion at the meeting and be out to the public in time for the spring tick season.

Transmission, Prevention and Tick Removal: The committee agreed on several changes to be made to the sections discussing ticks:

1. Since nymphs present the greatest risk for infection, focus first on that stage, stating why the nymph is especially dangerous. Emphasize its preferred habitat and the landscape features where it is most likely to be encountered, describing enough detail to help people be alert when they are in risky areas or involved in risky activities. Mention that nymphs are found in leaf litter, under logs and on the sides of trees. If room, consider explaining why they prefer those places. Consider whether it would be appropriate to mention nymphs may be found around stone outcroppings (since *Ixodes scapularis* are found abundantly on stone walls).
2. Strike the phrase stating that ticks don't fall from trees (since there are reasons to suspect they may but no proof that they do) but keep the statement that they don't jump or fly.
3. Change phrasing in 1st sentence of 4th paragraph to state "only nymphs and adult females" (to avoid suggesting adult males transmit infection).
4. Strike the phrase describing the size of the nymph by using a unit of measurement. In its stead, consider the best comparison – sesame seeds are too large, "period at the end of a sentence" too small. Poppy seeds are just right, although their size may not be commonly known. Use words "small" or "tiny" to differentiate WBL nymphs from other ticks.
5. State: "Infected ticks are found in at least 41 counties."
6. State that compared to mosquitoes, which feed for only 2 to 4 minutes, ticks feed for a long time, over several days. Checking one's skin for ticks when in tick habitat is thus a feasible prevention technique.

7. If possible, replace the words “feed” and “refeed” with more easily understood words or phrasing. “Bite” is insufficient, but “suck and spit” is probably too graphic.
8. Strike the sentence stating, “An infected tick must be attached and feeding for at least 24 to 48 hours.” (since a published study from CDC researchers describes LD infection resulting from an *Ixodes scapularis* female attached for only 14 hours.) Keep sentence stating, “If ticks are removed in less than 24 hours after becoming attached, then the chance of getting LD is very low.”
9. Strike the sentence stating, “An average of 1-2% of adult ticks statewide are infected with LD bacteria.” Work with committee to develop a description of tick infectivity that more accurately reflects risk of infection.

Describing tick infectivity: The committee had discussed ways to describe tick infectivity earlier in the meeting (see discussion about the legend for the tick map under “educating the general public” above). Although no final decisions were reached about exact wording, all believed it imperative to emphasize rates for the most important vector, the nymph, providing specific numbers to clarify that there is substantial risk for infection in California.

Dr. Lane suggested the phrasing, “In the only well-studied county, an average of 5 to 15% of nymphs have been found to contain spirochetes, versus an average of only 1 to 2% in adult ticks.” Ms. Merrill emphasized the need to give the full range for nymphs, specifying the high 41% figure, to counter the long-standing misconception about risk that has resulted from quoting the low infection rate for adult ticks so long and so often. She said part of the problem is that most people, including doctors, don’t know the difference between the adult and the nymph; all they know is it’s a tick. Dr. Kramer suggested stating the mean and range for both tick stages based on the published literature. Dr. Lane added it might be important to mention that infection prevalences in adult ticks go up to 6% in some populations and perhaps higher, for example in the East Bay studies done by the Contra Costa County Mosquito and Vector Control District. The brochure and other educational materials, including the website, should talk about the seasons of risk, addressing the high prevalence of nymphs in that context, perhaps adding that even though our infection rates in adult ticks tend to be so much lower, Californians still occasionally acquire infection from adult ticks, probably more so than in the Northeast, because of our mild climate. Ms. Hubbard thought comparing some of the known nymphal rates in California to those in the Northeast could also be valuable.

Front page: Drs. Kramer and Kjemtrup agreed to make every effort to replace the silhouette of California with the tick infectivity map and to pay attention to emphasizing contrast, altering its colors if necessary.

Introductory paragraph: The committee also agreed to:

1. Revise the second sentence of the introductory section to begin, “LD is caused by spirochetes, corkscrew-shaped bacteria called *Borrelia burgdorferi*…”
2. Strike the third sentence of the brochure stating, “A disease similar to LD has been seen in Europe and Asia since the 1920s.” If there is room, consider stating, “People can get infected in other states and countries,” but this may be less important than other messages.

Symptoms: Changes that should be made to the symptoms section included:

1. Revise the sentence describing development of EM to say, “… EM may occur approximately 1-30 days after the bite of an infected tick.”
2. State early in the symptoms section, or perhaps before it, that “as few as 20% of people bitten by nymphal ticks ever discover the tick.”
3. Add: “Even though the rash and/or flu disappear even without treatment, the infection may remain…”
4. Strike the word “arthritis” (twice). Use “Joint symptoms” as symptom category.
5. Mention other tick-borne infections and how they may complicate symptom picture and treatment. (Dr. Stricker will develop statement.) Refer to website for evolving information on these diseases.
6. Add Bartonella to the list of tick-borne infections.
7. Add more late symptoms.
8. Add more symptoms of central nervous system infection.

Diagnosis and treatment: The committee wished to:

1. Strike the 2nd sentence, “It may take longer to recover completely if antibiotic treatment is delayed until the symptoms of late LD appear” (since it implies full recovery will always occur).
2. As a new 2nd sentence, consider the suggestion, “The length of treatment may vary greatly depending on the extent and length of bacterial dissemination.”
3. In the 3rd sentence, replace the word “patients” with the word “people” and the phrase “as early as possible” with the word “immediately.”

VIII. Agenda items for the next meeting

Several issues raised or unfinished during this meeting were placed on the agenda for the next meeting:

1. Revision of Epidemiology Update article and its references,
2. Continuing discussion of Dr. Kjemtrup’s proposal for a physician education program and questionnaire,
3. Development of seminars for educating physicians and a video of them, and
4. Continuing discussion of DHS LD brochure.

IX. Public comment

Herb Dorken, Ph.D., said he is a behavioral scientist, a psychologist, new to this field although he has been reading the literature quite regularly. He hopes DHS' educational materials will state that the current vaccine is not recommended. He believes not so stating would pose a danger because some employers are inclined to demand its use for those working in risky areas. He believes the literature supports this concern.

Meg Hughes helps lead the Sierra Foothills LD support group. She noted that although she lives in an endemic area in Northern California, there are no doctors for her to refer people to. Three in her family have LD, and she spoke of how totally it has affected their lives, a day-to-day battle "from the time we get up in the morning to the time we get up the next morning." Her 75-year-old mother takes care of her instead of her taking care of her mother. "DHS is not our enemy;" she said. "Our enemy is LD. But DHS could be our help. We need healthy people to speak for us because we can't speak for ourselves. We're too sick and too tired." Because patients give decades of their lives, full-time, to dealing with LD, she asked the committee to take all the time it needs to change the brochure so that it is not like the old one, to change it drastically so there will be more help for the next generation. She's afraid her 4-year-old grandson has also been infected, and there are no doctors for him. Speaking about the Physician Questionnaire, she observed, "Most doctors can truthfully state they are comfortable with their knowledge about LD because they have the knowledge they have." When her Bb Western blot proved positive, for example, her internist thought he knew that "All women test false-positive."

Nancy Procurot, R.N., works with Dr. Terese Yang in Santee, where they see a great number of Lyme patients from all over the world, so she gets to "see first hand the devastation and frustration the disease causes." Most have seen many doctors over many years and now have long-term disseminated LD, which will take much longer to treat, because "In most states, if you say the word 'Lyme' to a doctor, they'll say, 'I don't want to treat you. Go somewhere else.'" She said some doctors "think it's a fad disease and treat patients like they're crazy. But they're not crazy." Rather "they are people who want desperately to get well. They want desperately for their family members to get well. They have no place to go to be treated." So she salutes and thanks DHS for addressing this problem.

She asked the committee to imagine a time and place when doctors recognized LD and knew how to treat it, and knew to treat it early so that people didn't have to suffer with it year after year after year. And to imagine walking into a doctor's office and saying, "You know, doctor, I feel awful. It all started with a sore throat and I had a fever. Then I got terribly congested. Now I have a cough; I'm coughing up yellowish-green sputum. I get short of breath so easily. My chest hurts. I really feel awful. You know, a friend of mine thinks it might be pneumonia." And what if

the doctor said to you, “Pneumonia? We don’t have pneumonia in California. I’ll send you over to a psychiatrist friend of mine, and he’ll give you some Prozac, and you’ll feel really good.” She added, “That’s what’s happening to Lyme patients. I hear it over and over and over again.”

Lynn Shepler, M.D., J.D., stated that direct physician supervision of public health professionals who are dealing with matters of clinical human medicine should be required by law. She believes physician supervisors at DHS are not educated about LD and expressed doubt that any has ever treated a Lyme patient. She agreed that providing balanced information and opinions on controversial LD issues is worth striving for but argued that achieving a truly balanced view about LD requires addressing how commercial interests, especially vaccine interests, have driven the evolution of scientific distortions that she believes amount to fraud. “Technology transfer laws now allow researchers to profit directly from their inventions and then propagate fictional versions of this disease that buttress their intellectual property.” She thus believes fairly presenting opposing views about LD requires providing full financial disclosures as well. She alleged that Yale projects earning $10 million a year off LYMErix and pointed to patents used in lab tests and vaccines as other potential sources of bias. She suggested that LDAC won’t be able to understand why patients are fighting so hard until these sources of bias are appreciated. She offered to share relevant information she has collected.

Dr. Kramer replied that physicians within DHS do supervise staff and approve documents. Her immediate supervisor is a physician. Dr. Kevin Reilly added that some DHS physicians have clinical appointments in infectious disease at the University of California, and some, although they don’t have long-term experience treating LD, do have a keen interest in it. He explained again that DHS’ role is not to come up with specific treatment recommendations, but rather to serve as a conduit of the information that is available in the peer-reviewed scientific literature.

Chris Pope said DHS’ plan to educate less than 5% of California physicians is “laughably small.” His greater concern is the education’s content, which he fears might be “just more of the same,” reinforcing the early notions about LD that were “obvious to rheumatologists, like the rash, the immune response, the arthritis.” He requested DHS become “open to scientific possibilities” like the possibility that the “unknown proportion” of seronegative LD patients is in fact a very large one.

Laurie Dahlquist also fears doctors will continue believing what they want to believe unless something more is done about educating them than simply sending them a video or a brochure, which she thinks they’re likely to “just toss aside” because of what they think they know. She wants LDAC to find a way to get physicians to actually attend a seminar and somehow require them to learn what’s necessary. She noted that rheumatologists believe that late LD symptoms are just fibromyalgia and say “there’s nothing you can do about it; you just have to learn to live with it.” She thinks physicians and the public need to know especially about nymphs because they can drop off before you notice them, so people don’t know

why they became sick. She asked how soon a county map about nymphal ticks would be available. Dr. Kramer responded that DHS doesn't have much data on nymphs because they are very hard to find. She added that DHS would put whatever data are available about nymphs on its website.

In response to a question from Barbara Barsocchini, Dr. Kramer said that VBDS, primarily Drs. Fritz and Kjemtrup, have taken over the responsibility of reviewing reported LD cases, working with the Surveillance and Statistics Section. She added that, in response to LDAC's request, DHS has expanded the information collected from case reports and now tracks reported cases that don't meet CDC surveillance criteria as well as those that do. Ms. Barsocchini was surprised in light of controversies about whether Malibu patients had clinical or serologic evidence of LD. She suggested the reporting staff might need to be expanded. Dr. Kramer observed that lack of reporting is a problem not unique to LD, but is also true of California's 69 other reportable diseases. Peggy Leonard of Grass Valley said she was told that when her local health department (Nevada County) sends in LD case reports, DHS rejects them for not meeting criteria. Dr. Kjemtrup replied that by the time reports reach DHS from counties, most, about 95%, do meet criteria. Ms. Hubbard suggested Dr. Kjemtrup explain the new expanded tracking to county health officials and see whether that increases reporting and alters its pattern.

Carole Martin, leader of Danville's support group, said the "California Perspectives" article "lies about California," and she was insulted that it carries the names of Drs. Kjemtrup, Kramer and Lane. She feared DHS was withholding the new press release from guests so it could "send out more false information behind our backs." Because there are still no doctors for people to consult when they have LD, she believes DHS needs to act immediately by sending Dr Stricker to educate them. She asked how long terms were for, and how LDAC members are voted in or out.

Dr. Kramer noted that the legislation doesn't specify terms, so the appointments are for as long as people are willing to serve, that the new press release had now been distributed to LDAC members, and that DHS had agreed that in the future LDAC would be able to advise on articles and news releases before they were sent out.

Dr. Lane explained that being acknowledged on a paper doesn't mean you agree with all the statements in it or that you have final approval of it. It means only that you've read the parts related to your field and offered suggestions. The authors choose whether or not to take your suggestions, and they are the only ones responsible for what the paper says.

Earis Corman thought the committee was wasting time arguing the wording of the brochure because no one will read it anyway and better ones are already available. The real problem, she said, is that doctors in California won't believe patients can have LD. She has neuropsychological proof of impairment, and they won't even

run lab tests. She believes DHS is not getting out information about LD to anybody -- not laypeople, not doctors -- and suggested good TV infomercials would do that best, as they did for the electricity shortage.

Myrna Vallejo hoped Dr. Bonta would understand that "We aren't politically motivated; we just don't want what happened to us to happen to our children; their lives thrown in the garbage." She said last time she told how she became crippled because no one would treat her; she'd thought once DHS heard our tragedies they would understand and help. This time she came to protest, because it was "completely immoral for the Department to send out those two publications. They will cause many people to get hurt. They intimidate doctors in various smart ways, saying there is no LD here, how hard it is to get infected and how easy to get rid of LD. Doctors will know very well what they really mean – that DHS thinks California doesn't have LD. 'Don't worry. Don't diagnose it. Don't over treat it.'" She said its references show how vicious the report was and asked why it wasn't shared first with Dr. Stricker, who "sees our miseries every day. You insult us, and I will not accept this to continue. I know you have to collect a salary, but use your morals. Use your humanity." She asked DHS to think about all the children who suffer from LD, about humble people who don't go to libraries to learn what is happening to them, about people in institutions labeled as mentally ill when in actuality they have LD. It is true that a lot of diseases aren't recognized and not reported, but this is the first time that doctors have been persecuted for treating a serious disease. This is a democracy; these things should not be happening here.

X. Closing comments and Adjourn

Dr. Lane observed it had been a lively meeting, more so than usual. He thanked everyone for coming and said the committee appreciated all the different opinions. "That's how all of us learn; we educate each other by bringing our own special expertise to a group meeting like this, and I think you'll find we'll continue to work on your behalf as best we can." He said everyone will be informed when the next meeting is scheduled, that next time there would be a microphone so guests could better hear the discussion and that, to the extent allowed by DHS regulations, copies of materials under discussion would be available. He added that he and other committee members not trying to beat the storm would remain to speak with anyone interested.